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Quality of Life of Adults with Pervasive Developmental Disorders and Intellectual Disabilities

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Abstract The purpose of this study was to observe quality of life (QoL) and global evolution of persons with Pervasive Developmental Disorders (PDD) in three different groups. Individualized programs for PDD were compared to traditional programs for intellectual disabilities. Behavioural disorders were repeatedly evaluated using the Aberrant Behaviour Checklist (ABC) and QoL once a year. Little research has investigated this domain due to methodological problems with a non-verbal population. Two preliminary studies of individualized programs showed a significant reduction in behaviour disorders over the course of the study. The recent inclusion of a control group indicates that a traditional program reduces lethargy/social withdrawal (ABC factor 2). A good QoL was measured for the three groups.

Keywords Quality of life · Adults · Pervasive development disabilities · Intellectual disabilities · Aberrant Behaviour Checklist · Behavioural disorders

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Introduction

Over the past few decades, the concept of Quality of Life (QoL) has been increasingly applied to people with intellectual disabilities and autism. A major problem of QoL measurement is that the subjects must have a speech level sufficient to answer for themselves. Many individuals with autism and Pervasive Developmental Disorders (PDD) have speech problems and all of them have communication problems. As a result, it is impossible to conduct direct studies of QoL for persons with autism, especially in a group that has little or no language ability (Persson 2000). Thus, it seems that the only possible means of investigating QoL is hetero-evaluation by a proxy (the person who responds for the handicapped individual) (Campo et al. 1996).

In one longitudinal study (Persson 2000), the author suggests investigating QoL of adults with autism and intellectual disabilities indirectly by measuring behaviours, skills and independence with the Adolescent and Adult Psycho-Educational Profile (AAPEP) (Mesibov et al. 1997). We strongly think that any treatment program should be evidenced-based, but it seems problematic to evaluate QoL through a functional evaluation of competence. This kind of evaluation is very important and very useful for working with this population but we believe that a direct measure of QoL is more appropriate for our work (Van Bourgondien and Elgar 1990; Van Bourgondien et al. 2003; Schalock 2005). The QoL construct is by definition composed of multiple aspects and integrates an analysis of micro- (individual and family), meso- (organizations and the service delivery network) and macro-systems (society and culture). In our paper, we focus on microsystems (individuals) and interpret QoL as the well-being of a person in an environment adapted to his/her needs.

We aimed to explore the QoL of different types of residential treatment programs for adults with PDD living in public institutions.

The first residential treatment program based on structured pedagogy, e.g. TEACCH, Treatment and Education of Autistic and related Communications Handicapped Children (Schopler and Mesibov 1985) that was specifically designed for adults with autism was developed in the 1970s and 1980s in the USA (Van Bourgondien et al. 2003; Van Bourgondien and Schopler 1990). In Switzerland, adequate, specialized programs for adults with PDD have been lacking over the past decade. Many adults with autism did not benefit from early intervention in childhood since it did not exist at that time. As a result, they usually have poor outcomes (Billstedt et al. 2005), and substantial behaviour problems can occur during adulthood. In an effort to reduce symptom aggravation, two residences in Geneva, Switzerland, which were aware of TEACCH, have implemented a program with a structured teaching method for adults with PDD called PAMS for the French "Programme Autisme Méthode Structurée". Through preventive techniques of behaviour management, the program focuses most of its energy on behavioural disorders such as self-aggression, aggression towards others and yelling as well as on autonomy. PAMS programs are tailored to address the heterogeneity of PDD since many different levels of cognition and autonomy coexist. Thus, the program shares common activities, maintaining some flexibility in response to each individual's needs (Van Bourgondien and Elgar 1990). Van Bourgondien et al. (2003) showed that the participants in a specialized treatment setting, based on the TEACCH psycho-educational model received significantly more stimulation, individualized instruction, and socialization experiences in the community than participants in other settings.

In two preliminary longitudinal studies, we assessed the evolution of behavioural problems since the PAMS residences were created (Galli Carminati et al. 2007a; Galli Carminati et al. 2007b). These studies showed reduced social withdrawal.

In the present study, we wanted to explore the level of QoL in Swiss institutions to determine if differences exist when specific residential programs for PDD exist or not. Evaluations by family members and by program staff were used and we suspected differences between these evaluations. We would like to specify that these data correspond to those reported in the literature. One study (Schwartz and Rabinovitz 2003), which included residents with mild to moderate Intellectual Disability who could respond to the questions themselves, tried to investigate the quality of the responses to the Life Satisfaction Scale (LSS) (Schalock and Keith 1993). The authors show that a family member is a more suitable QoL informant than a staff member who lives with and cares for the individual. The correlation between the responses of residents and family members is significantly greater if the family members and residents are close.

Additionally, we decided to observe behavioural disorders which are usually the cause of hospitalisation in psychiatric hospitals and "present barriers to successful integration into the community and unrestricted access to available educational, vocational and leisure opportunities" (Rojahn et al. 2003). Schwartz and Rabinovitz (2003) emphasizes the importance of combining a subjective evaluation of QoL with objectives measurements such as scales measuring behavioural disturbances. Our aim was to determine if these behavioural problems can be reduced over time. We hypothesized that behavioural problems, such as self-aggression, hetero-aggression, and social withdrawal, of PAMS residents would be less severe than those of the no-PAMS group or that these problems would diminish more quickly.

Furthermore, we hypothesized that a link exists between the improvement of behavioural problems measured with the Aberrant Behaviour Checklist (Aman et al. 1985a) and an increase in QoL.

Method

Setting

The present study included two experimental groups as well as a control group and was designed as a continuum of the preliminary studies mentioned above. The first experimental group, called PAMS1, was created in 2000. These residents live in apartments that each house eight persons. They visit workshops outside the residence for about 6 h a day and workshops accommodate six persons at a time. The experimental group called PAMS2 was created in 2002. These residents live in apartments that each house six persons. Workshops take place in the same building and accommodate one person at a time for a short period. The institution chosen for the control group was created in 1972 and is situated in a different district (Valais District) of Switzerland than the PAMS1 and PAMS2 groups (Geneva District). The residents live in two apartments, each housing eight persons. All of the residents have been living there for at least 20 years, since between 1972 and 1988. Workshops are located outside the building and accommodate eight persons at a time for about 6 h a day.

The PAMS approach is mainly based on principles derived from the TEACCH, whereas the control group benefits from a classical residential program implemented for all persons with intellectual disabilities. It is based on principles derived from several approaches, mainly from

the behavioural model. In the three different groups, rewards (verbal and material) are used to motivate residents and negative reinforcement is used to reduce behavioural problems.

Participants

Thirty (23 males, 7 females) adults in residential settings were included in the study. Age ranged from 24 to 62 (mean = 39.9, SD = 10.7). The participants live in three different residences: PAMS1 ($n = 10$), PAMS2 ($n = 9$), no-PAMS ($n = 11$). As shown in Table 1, all participants meet the PDD diagnosis as described by the ICD-10 (World Health Organization 1994). PDD diagnosis in our sample is largely represented by childhood autism (14/30) and PDD unspecified (11/30). Diagnoses were established on clinical evaluation by an experienced clinical psychologist and confirmed by a second independent evaluation. The symptoms of PDD are wide-ranging and the clinical picture varies from one individual to another. PDD is characterized by a triad of symptoms (impaired communication and social interaction and stereotyped behaviours) which must be present to differentiate PDD from profound intellectual disabilities (ID). Considerable caution has to be used to distinguish autistic-like features from cognitive immaturity related to ID. The Childhood Autism Rating Scale (CARS) (Schopler et al. 1988) was used to confirm diagnoses and to establish a symptom severity rating for each participant. Cut-off references were based on a study by Mesibov et al. (1989) using the CARS with adults. In addition, all study participants have Intellectual Disabilities (ID) as described by the World Health Organization in the ICD-10. Four participants (13%) had moderate ID, 19 (63%) had severe ID and 7 (23%) had profound ID (see Table 1).

Measures

The "Inventaire de Qualité de Vie en Milieu Résidentiel" (I.Q.V.M.R.) (*ndlr: Inventory in residential environment*) (Tremblay and Martin-Laval 1997) was chosen to measure QoL. This inventory was elaborated for individuals of any age in need of substantial support who live outside of the family environment. The objective of this inventory differs from other instruments of QoL measurement but corresponds to what Schalock (2005) considers as most essential: calculations of the concordance between the person and his/her environment. The questions aim to determine if the system of assistance and support has been adapted to the disability (physical or intellectual). In addition, some IQVMR questions aim to "*verify if the environment allows or encourages the expression of choices*" (p.42, Tremblay et al. 1997) (ex. "Can he/she choose something to eat every day?"). This objective is better adapted to our population, which is seldom capable of making choices or expressing themselves.

IQVMR comprises 80 items and covers eight different domains (individuality; self-determination; environment; health & security; social integration; leisure & recreation; specific needs; staff training & supervisory control), which are compiled to calculate a total score. Responses are graded on a three-point scale (0 = unattained goal, 1 = partially attained goal; 2 = attained goal). Each domain has ten questions and a score range from 0 to 20 points. The total score varies from 0 to 160. The validation study indicates a mean score of 116.34 (SD = 17.30). The IQVMR was completed two times for each participant by an experienced psychologist, once to collect a staff evaluation (consensus of two referents) and once for a family evaluation (usually the father or mother, sometimes the brother or sister). The family was assisted in a semi-structured hetero-evaluation to maximize the chances of collecting all data.

We also employed the "ABC" (Aman et al. 1985a) a 58-item questionnaire graded on a four-point scale (0: the behaviour is not at all a problem, 3: it is a very significant problem). Results can be grouped into five factors: F1- irritability, agitation, crying (15 items), F2- lethargy, social withdrawal (16 items), F3- stereotypic behaviour (7 items), F4- hyperactivity, non-compliance (16 items), F5- inappropriate speech (4 items). The frequency of behavioural episodes was also recorded. Higher scores indicate greater behaviour problems. The ABC was chosen as it has the advantage of a limited number of items in conjunction with a clearly established and validated factorial structure (Aman et al. 1985b, 1987, 1995; Marshburn and Aman 1992; Rojahn and Helsel 1991). The scale was designed for a population of individuals with mild to profound intellectual disabilities.

The CARS (Schopler et al. 1988) consists of 15 subscales. The person is rated on each subscale based on the clinician's observations of the person's behaviour throughout the testing and behavioural observation session. Staff reports are also taken into account and the mean of both evaluations is considered. The CARS includes items concerning socialization, communication, emotional responses, and sensory sensitivities. The clinician scores each of the 15 items from 0 to 4 with 0 indicating no impairment and 4 indicating severe impairment. Based on the child's combined score from the 15 items, he or she can be classified as having mild, moderate, or severe autism or no autism.

The psychotropic medication taken was verified for each group. The molecules have been divided into eight

Table 1 Participant demographics, first diagnosis, ID level (according to ICD-10), severity of autism (according to CARS), and mode of communication

Gender	Age	First diagnosis	ID level	Placement	Experimental group	CARS score at inclusion of no-PAMS group	Mode of communication
M	44	PDD unspecified	Severe	Residential	PAMS2	35.0	Signs/gestures
M	49	PDD unspecified	Profound	Residential	PAMS2	36.0	Speech
M	58	PDD unspecified	Profound	Residential	PAMS2	44.5	Non-verbal
F	33	Autism	Severe	Residential	PAMS2	49.5	Speech
M	55	Autism	Profound	Residential	PAMS2	34.0	Signs/gestures
M	30	X-fragile syndrome	Moderate	Residential	PAMS2	35.5	Speech
F	31	Autism	Severe	Residential	PAMS2	47.0	Non-verbal
M	43	PDD unspecified	Severe	Residential	PAMS2	31.5	Speech
M	62	Other childhood disintegrative disorder	Profound	Residential	PAMS2	52.0	Non-verbal
M	48	Autism	Moderate	Residential	PAMS1	35.0	Speech
M	43	PDD unspecified	Severe	Residential	PAMS1	44.0	Speech
M	40	PDD unspecified	Severe	Residential	PAMS1	52.5	Speech
M	41	X-fragile syndrome	Severe	Residential	PAMS1	34.5	Speech
F	51	Autism	Severe	Residential	PAMS1	50.0	Non-verbal
M	37	Autism	Severe	Residential	PAMS1	46.5	Speech
M	41	X-fragile syndrome	Severe	Residential	PAMS1	35.0	Speech
F	42	Autism	Severe	Residential	PAMS1	51.0	Non-verbal
F	58	Autism	Severe	Residential	PAMS1	39.0	Speech
M	32	Autism	Moderate	Residential	PAMS1	43.5	Speech
M	24	PDD unspecified	Severe	Home	No-PAMS	41.0	Signs/gestures
M	26	Autism	Severe	Residential	No-PAMS	43.0	Non-verbal
F	32	Autism	Severe	Residential	No-PAMS	49.0	Non-verbal
M	24	PDD unspecified	Severe	Residential	No-PAMS	30.0	Signs/gestures
M	43	Autism	Profound	Residential	No-PAMS	47.5	Non-verbal
M	24	PDD unspecified	Moderate	Residential	No-PAMS	32.0	Speech
F	41	Autism	Severe	Residential	No-PAMS	40.5	Signs/gestures
M	38	PDD unspecified	Severe	Residential	No-PAMS	35.5	Speech
M	24	Autism	Severe	Home	No-PAMS	43.5	Signs /gestures
M	38	Other childhood disintegrative disorder	Profound	Residential	No-PAMS	44.5	Non-verbal
F	45	PDD unspecified	Profound	Residential	No-PAMS	46.5	Non-verbal

categories (Fig. 4). For each group, the number of molecules taken from each category was calculated (ex. 1 person taking 1 antidepressant and 1 traditional neuroleptic = 2 people when 1 of them is taking an antidepressant and the other is taking a traditional neuroleptic).

Intervention

The two experimental groups, PAMS1 and PAMS2, are living in PAMS residential programs which focus on structuring time and space in apartments and workshops through visual aids to make the environment more predictable (pictograms, objects, pictures, signs, …). The PAMS program includes domestic activities (e.g. having breakfast, bathing, walking or watching TV) and/or educational activities (e.g. basic constructions, categorization of objects) (Galli Carminati et al. 2007a). Each resident has an individualized educational plan addressing daily activities and a standardized procedure is developed for each activity. Workshops are led by professionals with experience in autism. The activities are selected according to each resident's abilities, which were initially determined with the AAPEP assessment made when the resident entered the program. Goals are then adapted by the educational team every year or twice a year according to the individual's progress and needs. Finally, the continuity and effectiveness of the program is ensured by regular professional work hours and by strong team coherence.

The control group's program also incorporates time and space structuring in apartments and workshops and uses some visual aids, but contrary to the PAMS program, these strategies are not used with all residents. Although workshops include activities adapted to each resident's abilities and are also adjusted once or twice a year, these abilities were determined solely on the basis of professional observation.

Procedure

The study was approved by the Ethical Committee of the Geneva University Hospitals. A clear oral explanation was given to residents who were capable of understanding and their families during individual sessions. Residents for whom we could not obtain consent were excluded from the study but not from the residential program for logical ethical reasons. Staff members were blind to the study's goals.

Data collections for the ABC were carried out at 3-month intervals. Five observations were obtained for this study. All the residents were observed by the socio-educational team for one week and the ABC was completed with a psychologist.

The IQVMR was completed for the first time at the beginning of the study and then a second time after 1 year.

It was not possible to randomly assign the residents to a group. The residents in the control group live in a different district than the two other groups. For the two PAMS groups, the order of arrival in the institution determined the resident's inclusion in one environment or the other.

Data Analysis

For the IQVMR assessment analysis, parametric tests were not possible due to heterogeneity of variance so non-parametric tests were used (Kruskal–Wallis, Wilcoxon Signed Ranks, Mann–Whitney tests, Spearman's rho). For the ABC scale, we used a 5×3 Manova for repeated measures (5 observations $\times$ 3 groups) with Bonferroni corrections for multiple comparisons and *t*-tests.

Results

QoL results were examined first. Family and staff evaluations were analysed separately and then compared. In 2005, we obtained a high rate of completion, as 93.3% ($n = 28$) of staff assessments were completed but only 53.3% ($n = 16$) of family assessments. In 2006, 96.7% ($n = 29$) of educator assessments were completed and only 50% ($n = 15$) of family assessments. Almost half of the family assessments could not be completed for various reasons: some residents have no family at all or family members live abroad ($n = 8$), family members don't speak French ($n = 4$) and some families were not available to answer ($n = 4$).

As shown in Figs. 1 and 2, total staff scores for each group are higher than the validation sample (mean = 116.34, SD = 17.30). Total family scores are lower than the reference's mean.

While educators have 0% of non-response, families have 14% of non-response (range from 5 to 32%). As shown in Fig. 3, an inter-group Kruskal–Wallis-test on family non-responses showed significant differences in 2005

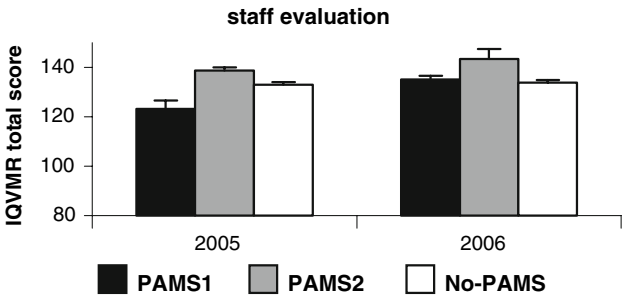

Fig. 1 IQVMR total score for staff assessments

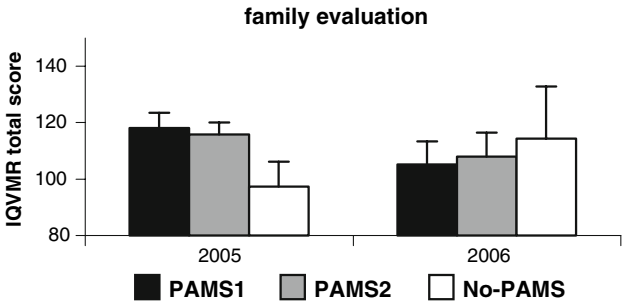

Fig. 2 IQVMR total score for family assessments

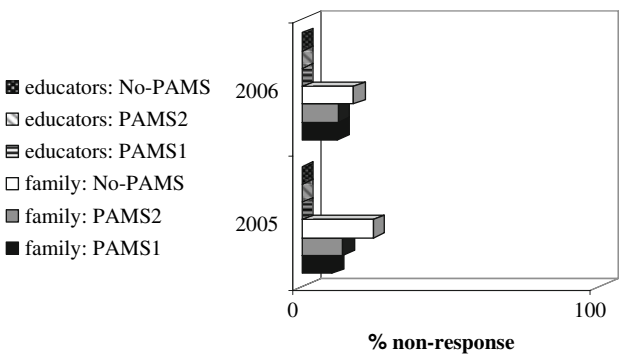

Fig. 3 Percentage of non-response for staff and family evaluations in 2005 and 2006

[$\chi^2(2) = 4.583$; $p > 0.05$] as well as in 2006 [$\chi^2(2) = 1.175$; $p > 0.05$].

Missing data in the family evaluations were especially prominent in the "staff training and supervision" domain (mean = 60%, min = 20% max = 100%). The amount of missing data was not as substantial in the other domains. In order to circumvent the problem to the amount of missing data between the three groups, the total score was divided by the number of items completed. The score obtained in this manner realistically reflects the responses given and is not influenced by the missing responses, which were attributed a score of 0 and reduced the QoL indicated. This modified score for the family evaluations was used throughout the analyses.

To determine whether there was a difference between the three groups in 2005 and then in 2006, we tested the differences in total score separately for staff and families. For this inter-group analysis of family assessments, the Kruskal–Wallis-test showed no difference between the three groups in 2005 [$\chi^2(2) = 3.995$; $p > 0.05$] or in 2006 [$\chi^2(2) = 0.203$; $p > 0.05$]. For staff assessments, the Kruskal–Wallis-test showed differences between the three groups in 2005 [$\chi^2(2) = 19.011$; $p < 0.01$] and 2006 [$\chi^2(2) = 8.389$; $p < 0.05$]. Two-by-two Mann–Whitney-tests on total IQVMR scores in 2005 showed that PAMS2 > no-PAMS > PAMS1 and that in 2006, PAMS2 = PAMS1 and PAMS1 = no-PAMS but also that PAMS2 > no-PAMS.

We hypothesized that IQVMR scores would improve over time. Therefore, we compared IQVMR total scores for each experimental and control group at the beginning (2005) and end (2006) of the study. For this intra-group comparison of 2005 and 2006, we performed a Wilcoxon Signed Rank test. For the PAMS1 group, while the total IQVMR score increased for staff between 2005 and 2006 (see Table 2) [$\chi^2(10) = -2.807$, $p < 0.01$], the total score for families decreased (see Table 3) [$\chi^2(2) = -2.201$; $p < 0.05$]. For the PAMS2 and no-PAMS groups, there was no statistical change between 2005 and 2006 for either staff or family (see Tables 2, 3). In any case, our groups are very small and the statistics must be interpreted carefully.

In order to compare the results between staff and families, the inter-rater reliability was verified between the family and staff IQVMR evaluations. Reasonable percentages of inter-rater reliability were observed for the different domains in 2005 and 2006 (see Tables 4, 5).

For 2005, the average inter-rater reliability is 70% and varies according to the different domains from 54% (social integration) to 96% (specific needs). For 2006, the inter-rater reliability is 69%. Most of these percentages are similar to the validation data which varied between 69% (staff training & supervisory control) and 88% (individuality and health & security). A detailed analysis of the inter-rater reliability for all of the 80 items shows that the level can attain 80%, or even 100%, for a majority of the items. It is interesting to see that one or two items in each domain have a poor (between 15 and 50%) inter-rater reliability. As in the validation study, certain items are more sensitive (ex: environment: item 6; health & security: item 9; leisure & recreation: item 6). For some items, the reliability is 0%, especially in the "staff training & supervisory control" domain, but it should be remembered that a great deal of data was missing in this domain in particular.

Our second hypothesis concerned the evolution of behavioural problems as measured with the ABC scale. Five ABC observations were recorded (March 2005, June 2005, September 2005, December 2005, and March 2006). A 5 × 3 Manova for repeated measures (5 observations × 3 groups) with Bonferroni corrections for multiple comparisons was computed for each ABC subscale. These analyses showed an interaction effect time × group on the irritability subscale [$F(8, 92) = 2.390$; $p = 0.22$] (PAMS2 > PAMS1 = no-PAMS) and a main effect on the lethargy subscale [$F(4, 92) = 4.277$; $p = 0.003$] with no interaction effect.

To complete this Manova, we performed a *t*-test for each group and each subscale between March 2005 and March 2006 (see Table 6). We found a statistically significant decrease on the lethargy subscale [$t(8) = 2.594$; $p = 0.32$] for the no-PAMS group. No statistical changes were found for the PAMS1 and PAMS2 groups.

As explained in the introduction, our research team has monitored PAMS groups since introduction of this method, in 2000 for PAMS1 and 2002 for PAMS2. An analysis from the very first observation of the PAMS groups was carried out. For the PAMS1 group, the evolution from December 2000 to March 2006 was examined. A *t*-test analysis showed a decrease on the lethargy subscale [$t(7) = 4.513$; $p = 0.003$] and no decrease on the other subscales. For the PAMS2 group, no statistically significant

Table 2 Number of IQVMR, means and standard deviations of staff IQVMR total score for each group

IQVMR total score staff	2005		2006		Wilcoxon Signed Rank test	
	N	Mean (SD)	*N*	Mean (SD)	*Z*	*P*
PAMS1	10	123.2 (10.5)	10	135.1 (4.7)	−2.807	0.005**
PAMS 2	9	139.9 (3.1)	9	143.6 (12.2)	−0.889	0.374
No-pams	9	132.9 (3.2)	10	133.9 (2.8)	−1.761	0.078

** Significance $p < 0.01$

Table 3 Number of IQVMR, means and standard deviations of family IQVMR total score for each group

IQVMR total score family	2005		2006		Wilcoxon signed rank test	
	N	Mean (SD)	*N*	Mean (SD)	*Z*	*P*
PAMS1	8	118.1 (15.4)	5	106.0 (22.5)	−2.201	0.028
PAMS 2	5	115.8 (9.7)	6	105.3 (18.2)	−0.105	0.917
No-pams	3	97.3 (15.3)	4	112.0 (26.7)	−0.535	0.593

Table 4 Percentages of inter-rater reliability between family and staff scores on each item of IQVMR in 2005

Domains of IQVMR	Items										Total
	1	2	3	4	5	6	7	8	9	10	
Individuality	94	31	100	63	100	100	94	87	60	81	81
Self-determination	14	36	14	93	36	80	80	80	79	87	60
Environment	82	63	50	60	83	38	53	73	73	31	61
Health & security	80	100	100	93	93	100	100	71	67	100	90
Social integration	46	40	44	50	43	25	19	94	94	85	54
Leisure & recreation	100	56	50	13	100	29	88	63	47	15	56
Specific needs	93	93	94	94	100	94	93	100	100	100	96
Staff training & supervisory control	100	50	78	90	71	0	0	100	80	75	64
Global											70

Table 5 Percentages of inter-rater reliability between family and staff scores on each item of IQVMR in 2006

Domains of IQVMR	Items										Total
	1	2	3	4	5	6	7	8	9	10	
Individuality	93	53	93	33	92	86	87	93	77	69	78
Self-determination	18	46	8	40	62	38	86	90	100	83	57
Environment	87	87	31	82	60	36	71	100	79	21	65
Health & security	92	85	100	100	93	100	88	100	87	100	95
Social integration	36	36	40	50	57	29	64	93	67	36	51
Leisure & recreation	100	67	57	27	93	21	80	86	23	18	57
Specific needs	87	93	100	100	100	100	92	92	100	100	96
Staff training & supervisory control	80	57	100	100	75	20	0	0	50	75	56
Global											69

changes were observed between December 2002 and March 2006.

In order to verify the hypothesis that a link exists between behavioural problems and QoL, non-parametric correlations (Spearman's rho) between ABC scores and IQVMR scores were analysed. We used the mean of the two ABC scores recorded before the IQVMR evaluations in 2005 and 2006. For this analysis, we did not take the "inappropriate speech" subscale into account since its validity is compromised by the fact that it is artificially scored at 0 when residents are non-verbal. Only the significant correlations have been indicated (see Tables 7, 8).

This analysis shows that behavioural problems are not related to the domains of QoL in the same manner for families and staff. Significant correlations are primarily seen with the domains of the IQVMR and not with the total score. For staff, little variation is seen between the 3 groups and from 1 year to the next. The irritability, lethargy and hyperactivity subscales of the ABC are negatively correlated to the domains "social integration" and "leisure & recreation." On the other hand, two positive correlations were found for the lethargy subscale, with the domain "staff training & supervisory control" for PAMS2 and with the total IQVMR score for PAMS1. Another positive correlation exists between irritability and "health & security". The lethargy subscale has more significant correlations than the other subscales of the ABC. It should be remembered that only the lethargy subscale diminished over the course of the study for the no-PAMS group. While it was significantly correlated to the domain "social integration" in 2005, this correlation disappeared in 2005 with the significant reduction in problems of lethargy. To

Table 6 Mean (standard deviation)

Groups	ABC subscales	First observation	Last observation	*t*-Test	
		Mean (SD)	Mean (SD)	*t*	*p*
PAMS1	Irritability subscale	4.78 (5.04)	7.89 (6.90)	−1.56	0.156
	Lethargy subscale	11.78 (12.65)	8.33 (10.15)	1.51	0.169
	Stereotypy subscale	8.56 (4.25)	7.45 (3.21)	0.84	0.427
	Hyperactivity subscale	10.33 (10.38)	9.44 (6.86)	0.26	0.805
	Speech subscale	4.22 (3.63)	3.78 (3.11)	0.94	0.377
PAMS2	Irritability subscale	16.89 (9.64)	12.78 (9.67)	1.15	0.282
	Lethargy subscale	11.11 (7.79)	6.89 (3.26)	1.83	0.106
	Stereotypy subscale	6.67 (5.52)	3.67 (4.39)	2.17	0.062
	Hyperactivity subscale	19.67 (11.45)	12.33 (10.34)	1.61	0.145
	Speech subscale	3.33 (4.03)	2.33 (3.43)	1.46	0.184
no-PAMS	Irritability subscale	8.22 (6.50)	6.22 (3.99)	1.12	0.294
	Lethargy subscale	17.78 (6.40)	10.67 (7.30)	2.60	0.032*
	Stereotypy subscale	8.67 (3.35)	7.78 (1.20)	0.77	0.466
	Hyperactivity subscale	16.33 (10.92)	12.11 (9.68)	1.68	0.132
	Speech subscale	0.56 (1.13)	0.44 (1.01)	0.29	0.782

* Significance $p < 0.05$

Table 7 Significant Spearman's rho (r_s) correlations between ABC scores and IQVMR domains and total scores of staff evaluations in 2005 and 2006

Domains of IQVMR	ABC subscales							
	Irritability subscale		Lethargy subscale		Stereotypy subscale		Hyperactivity subscale	
	2005	2006	2005	2006	2005	2006	2005	2006
Individuality								
Self-determination								
Environment								
Health & security	PAMS1: $r_s = 0.65$*							
Social integration			No-PAMS: $r_s = -0.69$*	PAMS2: $r_s = -0.70$*			PAMS1: $r_s = -0.70$*	
Leisure & recreation	PAMS1: $r_s = -0.71$*	No-PAMS: $r_s = -0.63$*						No-PAMS: $r_s = -0.71$*
Specific needs								
Staff training & supervisory control			PAMS2: $r_s = 0.68$*					
Total score				PAMS1: $r_s = 0.71$*				

Note: * Significance $p < .05$

summarize, for staff, the correlations indicate that if behavioural problems (irritability, lethargy and hyperactivity) increase, social integration and leisure decrease. For PAMS staff only, if irritability and lethargy problems decrease, "health & security", "staff training & supervisory control" indicators and the total score also decrease.

For the families, the significant correlations are numerous and they are more widely distributed across the different IQVMR domains than for staff. Each group has a different number of significant correlations: PAMS2 ($n = 10$), no-PAMS ($n = 5$) et PAMS1 ($n = 1$). The number of significant correlations decreases between 2005 ($n = 12$) and 2006 ($n = 4$). Significant negative correlations were observed between the four subscales and the seven domains as well as the total score, except for the "individuality" domain.

For the families of PAMS2, as for the PAMS2 staff, a positive correlation is seen between the lethargy subscale and "staff training & supervisory control."

The psychotropic medication taken by each group was verified (see Fig. 4). Molecules from the 8 categories are generally used in the PAMS groups. In the PAMS1 group,

Table 8 Significant Spearman's rho correlations between ABC scores and IQVMR domains and total scores of family evaluations in 2005 and 2006

Domains of IQVMR	ABC subscales							
	Irritability subscale		Lethargy subscale		Stereotypy subscale		Hyperactivity subscale	
	2005	2006	2005	2006	2005	2006	2005	2006
Individuality								
Self-determination			No-PAMS: $r_s = -1.00$**					
Environment	PAMS1: $r_s = 0.85$**		PAMS2: $r_s = -0.95$**					
Health & security			PAMS2: $r_s = -0.80$*		PAMS2: $r_s = -0.85$			
Social integration		No-PAMS: $r_s = -1.00$**			No-PAMS: $r_s = -1.00$**		PAMS2: $r_s = -0.81$*	
Leisure & recreation		PAMS2: $r_s = -0.89$*	PAMS2: $r_s = -0.87$*					
			No-PAMS: $r_s = -1.00$**					
specific needs			PAMS2: $r_s = -0.91$**					
Staff training & supervisory control				PAMS2: $r_s = 0.85$*	PAMS2: $r_s = -0.77$*			
Total score			PAMS2: $r_s = -0.95$**		No-PAMS: $r_s = -1.00$**			

* Significance $p < 0.05$

** $p < 0.01$

residents mainly receive atypical neuroleptics and mood stabilizers. PAMS2 residents received the same molecules, but neuroleptics and antiparkinson medications remained the preferred treatment for this group. In the no-PAMS group, neuroleptics and mood stabilizer are the primary treatments with a few mood stabilizers and phytotherapeutic treatments. There are no diagnostic differences between the groups which could explain the different treatments. The medical cultural differences that exist between the two districts explain the different use of treatments at the physicians' disposal.

Discussion

Overall, QoL, as estimated by the IQVMR, is good in Switzerland and better than the reference mean (Tremblay et al. 1997) when evaluated by staff. The QoL measured by PAMS1 staff increased as hypothesized and in 2006 attained the same level as the PAMS2 and no-PAMS groups, which remained stable between 2005 and 2006. Results of family evaluations are inferior to those of staff and below the reference mean. The high rate of non-response artificially decreases the mean of each group. In order to avoid biasing intra- and inter-group analyses, we had to calculate the scores in proportion to the number of questions to which the families were able to respond. Through these modified scores, the analyses showed that total family IQVMR scores for the PAMS1 group decreased during the study period. This surprising difference can be explained either by an accurate evaluation of a decreasing QoL or by an overly positive evaluation at the beginning. In any case, two important points must be kept in mind while interpreting family IQVMR total scores and comparing them to the reference's mean. First of all, only half of the families replied and secondly, a great deal of information was missing from the family evaluations. The amount of data missing from family evaluations was especially striking in the "staff training and supervision" domain of the IQVMR. The families are often unaware of institutional policies concerning the level of training required and the offers of continuing training for staff. Parents, who are not specialists of the assessment method, are often not used to certain vocabulary and thus have great difficulty understanding some of the questions. This is not surprising as the IQVMR is not meant for non-professionals. For this reason, we carried out real interviews with parents, the only method to obtain IQVMR data. The

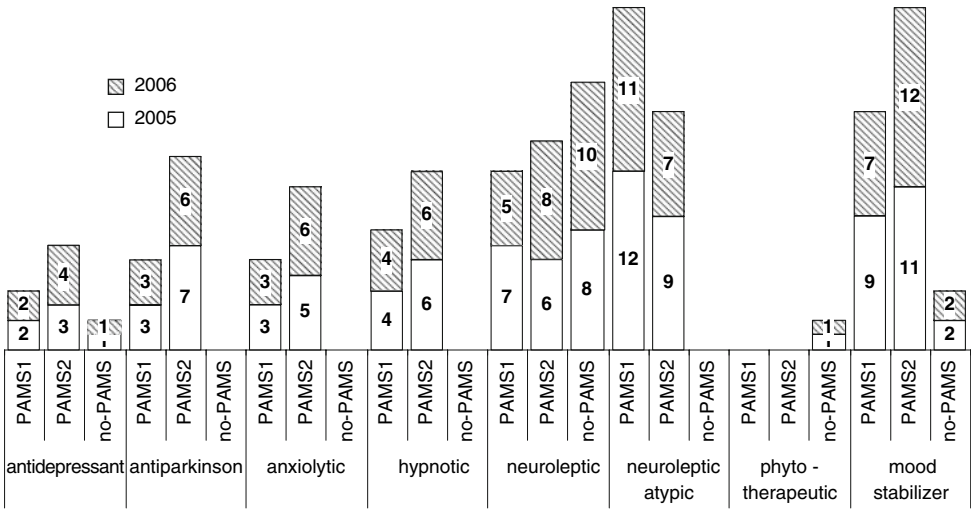

Fig. 4 Number of molecules in each category and for each group at the beginning (2005) and the end of study (2006). Phyto-therapeutic is millepertuis which is known for its antidepressant effect; mood stabilizer also includes antiepileptic treatment

staff's knowledge of this type of assessment allowed us to merely supervise administration of the questionnaire, and this method seems to have functioned correctly because the staff assessments were fully completed.

Inter-rater reliability between family and staff IQVMR evaluations was assessed. It was globally converging even if a lack of consensus for certain items was observed. The families and the staff noted that certain questions were poorly adapted to PDD residents (ex: "*has at least one friend of the same age*", "*has the opportunity to participate in a hobby*", "*has access at all times to his/her identity papers*"). The IQVMR validation study only included 2 cases of autism among the 99 participants.

With all these remarks in mind, we could suggest that the persons with PDD reality lies somewhere between the results of the two evaluators. In any case, educator staff and the management of the institutions have reported a positive effect of the study. Our investigation has enhanced discussion between parents and staff, stimulated reflexion and allowed parents to ask the educational teams questions. These questionnaires may also provide families with the opportunity to air their difficulties, criticism and distress, and in this sense this project makes it possible to improve partnerships with the institutions. The results have encouraged discussion about managing individuals with autism and directly linked families to the care given to their children.

Concerning behavioural problems, the present study shows that PAMS2 has a higher score on the irritability subscale than other groups. A statistical decrease on the lethargy subscale was only noted for the no-PAMS group. Thus, we could not entirely validate our hypothesis that the PAMS groups would present fewer behavioural disorders, as measured by the ABC, and that QoL, measured by IQVMR, would simultaneously increase.

When analysing these results, it must be kept in mind that the recent inclusion of the control group forced us to compare them with the very last observation of the PAMS groups. The comparison with the control group was carried out 3 years after the introduction of PAMS and the first benefits of PAMS introduction cannot be seen with truncated results. An analysis of incomplete data from PAMS groups could have artificially led to stability. To control for this, a detailed analysis of all the data going back to the very first observation of the PAMS groups was performed. For the PAMS1 group, we calculated the evolution from December 2000 to March 2006. The analysis showed us a decrease on the lethargy subscale and no decrease for other subscales. For the PAMS2 group, stability was observed for all factors between December 2002 and March 2006. Thus, we could partially validate our hypothesis that PAMS programs have a positive impact on behavioural problems, as measured by the ABC scale. This is true only in the PAMS1 group and for the lethargy subscale, which covers not only lethargy items but also social withdrawal.

How can we explain our results? The PAMS population didn't benefit from adapted treatment in their early childhood. Unfortunately they now suffer from chronic behavioural problems. This lack of treatment may have had a greater impact on PAMS2 participants. Another hypothesis is that certain characteristics of the PAMS program do not suit all participants. It may be necessary to modify PAMS for individuals with greater intellectual disability. As suggested by Sherer and Schreibman (2005), differential responsiveness to intervention programs suggests the inadequacy of a single treatment approach for all children with autism. In a way, the PAMS programs try to address this important criticism of uniform treatment for autism.

The analysis of the correlations between behavioural problems and QoL show that behavioural problems are not related to QoL in the same way for families and staff. For staff, irritability, hyperactivity and lethargy interfere with social integration and leisure & recreation. For families, the

four ABC subscales are negatively correlated to all of the IQVMR domains, except individuality. Only one of the IQVMR indicators, "staff training & supervisory control," is positively correlated to problems of lethargy for families and staff of the PAMS2 group. Our results are quite similar to observations of a previous study. Indeed, Felce et al. (2002a, b) showed that a high proportion of qualified staff predicted a lower level of resident participation in domestic tasks and was otherwise not shown to be a positive attribute. The results also show that the number of significant correlations between QoL and behavioural problems decreased between 2005 and 2006, independently of a decrease in behavioural problems.

The first limitation to our study is that we observed individualized treatment plans but we chose to use a group analysis, leading to the loss of some clinical data. We observed 2 distinct profiles with very different patterns of reaction to the introduction of PAMS: for some participants, reductions were seen for a majority of their behavioural problems while others presented a chaotic profile throughout the observation period. This kind of chaotic profile is found in most participants in the PAMS2 group, which probably explains our results. Of course, a randomized assignment design would have been required to clarify results. A third limitation is that the time of integration in each residential program could not be controlled. PAMS residents integrated the study as they arrived in the PAMS apartments whereas no-PAMS residents had lived in their apartments for a long time.

Group analysis is also limited by its statistical power. This a posteriori analysis showed that each group should have between 10 and 100 participants in order to show statistical significance. Obviously, there are no residential groups with so many participants and recruitment in this research field is difficult. As we observe individuals, we must deal with the heterogeneity of PDD profiles. Thus, we evaluate evidence-based practice and not evidence-based research with a randomized sample. Treatments are adapted to individual needs, which is the problem of "non-standardized procedures" (Sherer and Schreibman 2005). It is difficult to explain exactly which methods works for which subjects, but this is the goal that research today must strive towards. Our future research should definitely seek to clarify this point by analysing differences according to age, cognitive level, and chaotic versus stable evolution patterns.

The major strength of this study is its longitudinal and prospective design. Such a long observation has the major advantage of providing information about the evolution of this challenging population. Such a design demands a great deal of energy and money but makes it possible to consider possible ways to adapt PAMS if we need to increase the programs' effectiveness after the study. As the socio-educational teams were blind to the results, they were asked to do what they felt was best for their residents and were allowed to change programs and activities depending on the needs of the resident. Another major advantage of our experimental design is that no extra contacts were made with residents, which probably results in less stress for them.

Additionally, this kind of study provides the opportunity to enhance collaboration with families and make an effort to continue this partnership.

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